DOCUMENT RESUME

ED 374 610 EC 303 332

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TITLE A Qualitative Study of Self Advocacy and Guardianship: Views from New Hampshire.
INSTITUTION Community and Policy Studies, Syracuse, NY.
PUB DATE 93
NOTE 32p.; For related documents, see EC 303 329-331 and ED 355 735.
PUB TYPE Reports - Descriptive (141)

EDRS PRICE MF01/PC02 Plus Postage.
DESCRIPTORS *Advocacy; Caregiver Role; Case Studies; *Developmental Disabilities; Qualitative Research; *Self Actualization; Self Determination; *Self Help Programs
IDENTIFIERS *Guardianship; New Hampshire; *Self Advocacy

ABSTRACT

This qualitative research case study includes a brief overview of the status and development of self-advocacy in New Hampshire, describes the state's guardianship program, and highlights areas of concern to people with disabilities. Self-advocacy is described as having three primary components: (1) enabling people with developmental disabilities to speak for themselves; (2) joining together with others to achieve systems changes through advocacy strategies; and (3) sharing social and personal support offered by local self advocacy groups. The desired outcomes of self-advocacy are listed a marriage and family, jobs one likes to do with good pay, a "dream" career, a comfortable place to live, freedom to come and go, housing, adult education, results or individual services plans, clothes and equipment, and transportation. The study describes the role of local self-advocacy groups, roles within groups, roles of advisors and supporters, and future issues. (JDD)

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ED 374 610

A QUALITATIVE STUDY OF SELF ADVOCACY AND GUARDIANSHIP: VIEWS FROM NEW HAMPSHIRE

COMMUNITY AND POLICY STUDIES

EC 303332

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A QUALITATIVE STUDY OF SELF ADVOCACY AND GUARDIANSHIP: VIEWS FROM NEW HAMPSHIRE

Julie Ann Racino

COMMUNITY AND POLICY STUDIES
Syracuse, New York

1993

This is one in a series of qualitative studies on state and national practices in deinstitutionalization and community integration and the changes that will be necessary to promote full participation of people with disabilities in all aspects of community life and daily policymaking. This qualitative study is based on research site visits to the state of New Hampshire conducted in Fall 1991 and Summer 1992.

The author extends particular thanks to Roberta Gallant, Jane Hunt, Jocelyn Gallant, Alan Emerson, Janet Hunt-Hawkins, Michael Cassassanto, Bindy Bourgeois and Jean Delphia for their assistance with this case study. Thanks also to Perry Whittico, Mary Hayden and Ginny Harmon for their insightful review and commentary on an earlier draft.

> I really feel strongly about self advocacy because no one can speak as effectively for an individual human being than that individual human being.
>
> - A New Hampshire Advocate

Self advocacy is part of a growing movement across the United States and is discussed here as a counterpoint to the beginning shift in New Hampshire from a service system dominated by providers and state employees to one in which families are recognized and supported[1]. This case study raises the question, "How will this shift to family-centered systems include what people with disabilities themselves want and need?"

This qualitative research case study includes a brief overview of the status and development of self advocacy in New Hampshire, describes the state's guardianship program, and highlights areas of concern to people with disabilities. In particular, the research reflects upon the meaning of self advocacy, its development, local self advocacy groups, the role of advisors and supporters, future issues, and desired outcomes of self advocacy.

The Meanings of Self Advocacy

Self advocacy has a variety of meanings to people with and without disabilities both based on their own personal experiences and beliefs about what advocacy means. Self advocacy in New

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[1] For more information on family support development in New Hampshire, see Shoultz, B. (1993). Like an angel they came to help us: The origins and workings of New Hampshire's family support network. (Available from: NARIC, 8455 Colesville Rd., Suite 935, Silver Springs, Maryland 20910).

Hampshire has three primary components: (1) Enabling people with developmental disabilities tc speak for themselves, (2) Joining together with others to achieve systems changes through advocacy strategies, and (3) Sharing social and personal support (known as peer support in the independent living movement) offerred by local self advocacy groups.

Speaking for Oneself

In one sense, self advocacy is about speaking for oneself. This may be as simple as calling the vocational rehabilitation counselor for the first time. For another person, it may mean indicating by expression that she would like a glass of water. Some people might not call these actions self advocacy. However, these are steps in building the persons's own confidence that she knows best what she wants and can translate these desires into actions.

Self advocacy is about decisionmaking and about self worth, and is one of "the ingredients to becoming more self determined." Being part of a self advocacy group means that a person may be able to get what he wants, whether an apartment, a job, or simply being heard ("I could be independent, and maybe find an apartment and someone to live with me. I could kind of like be on my own.") The hope is that people with developmental disabilities will learn more about what they want, express it, and have at least some of their desires met.

Joining Together With Others

Self advocacy also means joining together with others to achieve systems change that affects the well being and lives of others. As the treasurer of one self advocacy group described, this means using legislative advocacy strategies such as writing letters to Congress "to get the government behind you." As he explained,

> Self advocacy...is a way to get your problems solved...if you get the government behind you 100%. I think writing letters to Congress is going to improve a lot...because we're going to get what we need...We've done our part. So now it is up to them to do theirs.

In this view, self advocacy means that people with disabilities can "fight" for the services that they want. It is based on a framework that the government should provide these services, particularly in instances where they have been previously denied by virtue of institutionalization.

People can become involved with self advocacy for many reasons, including the wish to "make a difference" ("you could help other people make better lives for themselves"). As one man who has been involved in the movement described:

> Yes, I think we've made a difference. I think we've gotten people moving...excited...I think we've made the point for some people who need to have...a little bit more help than others.

From the viewpoint of professionals, one of the reasons self advocacy is important is because the legislators listen more to people who are affected by and care about an issue. Self advocacy allows professionals to play a background role by providing information, education and resources, while the people most

concerned are in the forefront. As one advocate illustrated:

> If I go to testify to the state legislature (about)... motorized wheelchairs...who cares? Why don't we get some people who use motorized wheelchairs to go? Why don't we alert them and say, "Do you know the state is considering not paying for that anymore?...I just thought I'd pass that information on to you."

Social and Personal Support

Being part of a self advocacy group also means having a place to meet other people, "to make new friends, and to unite old friends, and to be independent." For parents, it may also be an opportunity for their son or daughter to be out of the house participating in a different activity.

In self advocacy, there is also the support of a "group behind you to guide you along" in making choices and decisions. This is similar to the concept of peer support in independent living which helps to "kind of gear someone up or put a little fire in them" to make decisions and face issues in their lives. These social and personal support aspects of self advocacy groups are illustrated further in the section on local groups.

Desired Outcomes of Self Advocacy

The desired outcomes of self advocacy vary with individuals and groups. However, in this study in New Hampshire, they included the following: marriage and family, jobs one like to do with good pay, a "dream" career, a comfortable place to live, freedom to come and go, housing, adult education, results on individual service plans, clothes and equipment, and transportation.

Marriage and Family

One area that sometimes is neglected with people with mental retardation is the desire many people have to date and form relationships, to marry, and to create families of their own with children they can care for and about. Like the woman below, these seem like reasonable hopes of what life in the future might hold:

> J: When you think about decisions in your own life, are there any big decisions right now that you need to make?
> B: Just to get an apartment and a roommate, and maybe down the line maybe find someone to marry and maybe adopt a child...
> J: So you think you'd be able to adopt?
> B: Yes, I'd like to adopt. I think I would be a good mother.

Jobs

Work is an important issue, whether it is finding a job that you like to do, getting along with the people who work there, or having the money and benefits that jobs provide. One man described the period when he was out of work and looking for a job:

> A: I didn't have money and I didn't have a job either. At that time, it was hard to find jobs because there aren't many out there that, there aren't many good jobs out there.
> J: Tough times.
> A: Yeah, it was tough for me because I can't read or write very well so it was tough trying to find a job, you know, trying to find a job that you can do.

Another woman shared her frustration with being underemployed and being made to take jobs that she views as demeaning because she was denied a good education when she was younger through her institutional confinement. She forcefully stated,

> Many of us who are (still) undereducated, okay, we (feel we) are made...to take jobs in cleaning, pushing broom handles all day long because of the fact vocational rehabiliation just doesn't (seem to) want to increase our education.

This same woman shared that she could make more money if she was trained in word processing and was able to perform clerical jobs in an office ("We should never have to be victimized...because we are undereducated.") Having a job that pays well enough to compensate for the loss of benefits is an important consideration in people's lives and decisions. She continued:

> I don't like the fact that (every)...time any of us get a job, welfare and social security always takes our benefits away from us, when we have a job that doesn't even pay us well. ..The paychecks that we get do not fit today's cost of living at all.

Obtaining a job can mean the loss of food stamps, a subsidized apartment, personal assistance, and the need to absorb even more expenses such as providing transportation to and from the job. These disincentives to employment in New Hampshire have become so acute that as the independent living center informants reported, some people with physical disabilities who are graduating from college are unable then to afford to go to work.

The Career of My Dreams

Just like other people, sometimes people with disabilities have a job, and also in the back of their minds and heart the hope of a dream career. One man described how his personal love of dancing and singing, entertainment, is something he might capitalize on someday:

> I've thought of maybe someday going ahead and, you know, putting my singing and dancing together and making a career of it. But I think I am going to wait until, you know, (until I) either get laid off or lose my job in order to start this career...So, this is something I am looking forward to trying.

A Comfortable Place To Live

The places where people live also make a difference in whether they are satisfied with their lives. What is comfortable varies with each person and what seems inconsequential to one person may be critical to another. One man described a living situation that made him feel very uneasy and affected whether he would invite friends in to visit.

> What these apartments were, they're almost like studio apartments...But you see I didn't have a bedroom in these apartments...It was kind of embarrassing. I didn't want people to see an apartment that didn't have a bedroom.

A comfortable place may also mean having a roommate that you can get along with. In describing her anticipated choice of a roommate, one woman shared that she would like "one that doesn't smoke, and one that I can get along with and that we can share responsibilities, for instance, shopping and cooking and I won't have any arguments with."

Freedom To Come and Go

Having one's own "pad" or place to liveis also significant, especially when it implies "freedom" which is a more common word for self-determination. This freedom can be signified by little things such as keys, or being able to sit and rest when one wants to do that.

> This is my own pad. I have my own keys and I come and go as I please...I don't have to come and answer to somebody because there's nobody to answer to, know what I mean? I come home and sit if I want to.

Freedom also means being in a place where staff are not always telling you what to do. One person described how staff would be "watching you to make sure you didn't get in trouble" and you had to get used to "watching what you said because if you said something wrong...you'd have a staff person (there)." Recounting this experience, the person said it was the job of the staff to "kind of like com(e) in and check...making sure you go to work, making sure you had money to pay your bills... And if you didn't have money you couldn't stay there."

Housing

Staff at the independent living center noted that housing for many people with disabilities was a big issue. Accessible, subsidized apartments were congregated together in units, which was not the way people with disabilities would choose to live.

> Housing is a pretty big issue in this state. Pretty much what they've done is they've grouped, they've sort of ghettoized... You live in a 24 unit (building). Everyone has a disability.. or just like an elderly-disabled mix...They wouldn't choose to live there on their own.

This contrasts with housing through the developmental disabilities services system in this state whereby people commonly live with just a few other people, by themselves, or with a roommate. As one advocate said:

> You'll find very few people in this state with developmental disabilities who live with more than 2 or 3 other people who have developmental disabilities. That's real step forward in a setting where you can get somebody to pay real solid attention to you, alone, yourself, for periods of time.

Education

One informant expressed concern with how the Individuals with Disabilities Education Act (IDEA), passed by Congress and signed into law by Gerald R. Ford in 1975, was designed and the implications for her own life. She believes the law should be expanded to include adults with disabilities over the age of 21 as well as children, especially for people who had been institutionalized ("it's a very unfair law.").

> I am not happy with the way Congress in Washington had designed...(part of the) legislation called the Individuals with Disabilities (Education) Act and I'll tell you the reason why...It's very unfair to people like me...who were denied a good foundation, a basic elementary and high school education against our will by the state while we were at Laconia State School for so many years.

She said existing adult education programs did not meet her needs because they concentrated more on socialization ("like little children") than on the basic skills such as spelling or reading which she would need to obtain a good job or drive a car.

Individual Services and Service Plans

Other concerns were related to individual service plans, including having individual service plans (ISPs) actually result in what the person wants accomplished and having opportunities for self advocates to participate in agency decisionmaking regarding service planning.

One woman vividly described that she wanted to see results and "not just broken promises." While people with disabilities have a

chance to "bring up the services we want," she doesn't feel people follow through to make these goals become a reality. Another person suggested that people with disabilities should be involved in making agency and systemic changes in the individual service planning process. Relatively little has been done about how "the service delivery system" could be impacted by self advocacy.

Clothes and Equipment

People also want clothes, computers, or other kinds of basic and more luxury items that they might not be able to afford on their budgets. Sometimes the lack of money for these items can also make a person feel like they are being ignored or not cared about. Other times, it may be that a person knows someone who has been able to buy something that they would like to own, such as a computer typewriter. They then aspire to purchase a similar item.

Transportation

Transportation was repeatedly underscored as one of the major issues that people with all types of disabilities face. The public trans- portation system in New Hampshire is practically non-existent, particularly between towns or in the more rural areas. One woman who has taken this on an issue, describes the problem this way:

> The entire state of New Hampshire really ought to have mass transportation period, especially for those who do not drive around...It is a hell of a problem period.

This self advocate described a number of strategies to try to

advocate for change, such as her participation in a federal hearing on transportation held in Maine. She said nothing happened as a result of her efforts, partially because the federal and state government tend to ignore problems ("This is true. They have a tendency to ignore problems.")

Transportation problems extend to getting to self advocacy meetings and to activities, including vacations. While the Lakes Region area agency office, in particular, has been generous with the use of their vans, getting access to this valuable commodity is not as easy as people would like:

> We need to have those vans and if we need to have them, we've got to have them...We can't force people to do that for us, but we need those vans. Because otherwise, we wouldn't be able to get to meetings...we wouldn't be able to do our...dances, we wouldn't be able to get to places that we need to go.

The lack of one's own transportation can make community recreation and work not viable options ("maybe there aren't a lot of recreational opportunities everywhere, but if you can't get there, it's almost a moot point anyway."). As one of the women at the state's independent living center described:

> Because there is none in the state, it pretty much means your own transportation and that is either a van or a modified car. For some people, it even means a driver and there is no funding in the state for that right now.

The Development of Self Advocacy in New Hampshire

In October 1984, the New Hampshire Developmental Disabilities Council, in cooperation with the Center on Human Policy at Syracuse University, sponsored a conference on self advocacy held on the

seacoast. The conference inspired a young woman, who together with another woman case manager, recruited people for a self advocacy group in the Laconia region. The group started about March 1985, mainly as a social group, and she became their advisor.

The Lakes Region self advocacy group has been meeting since then, and has had a number of other advisors, including a man who was the pastor at Laconia State School and who then worked at New Hampshire Hospital. One co-advisor previously was with Speaking for Ourselves[2] from Pennsylvania, a nationally known self advocacy group. Table 1 describes three people who are or were members of the Laconia self advocacy group, the strongest in the state.

The state Developmental Disabilities Council (DDC) was the springboard for a number of local groups, which used to meet statewide every month in the mid to late 1980s. The project then faded on the state level until January 1990 when the Council and the arc (previously the Association for Retarded Citizens) decided at the request of a young energetic woman in Concord to assist people to meet again.

A statewide conference was held in Manchester in June 1990 with over 100 self advocates attending. As one advocate described the event, "It was amazing...messy, disorganized, and so powerful I couldn't believe it." All the presentations were done by self advocates with sessions on how to be an advisor, how to start a self advocacy group, and the Americans with Disabilities Act (ADA).

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[2] Speaking for Ourselves, Lakes Region Self Advocacy, Laconia State School and New Hampshire Hospital are real names.

Table 1
A Few Of The People

Samuel Ellsworth[3]

Samuel was one of the "first pioneers" with the Lakes Region self advocacy group. He was elected the group's treasurer and was one of the co-chairpeople when the group first started. According to the group's advisor, he has gone through cycles where self advocacy was more or less important to him. Samuel is described as "well liked by people," "friendly" and a "good guy."

Samuel lives in his own place downtown and has a job at a local restaurant washing dishes. His girlfriend, Susan, also belongs to the self advocacy group. Samuel also loves music and "takes it with him wherever he goes," including when he rides his bike. He says at work he can "get people going" and the waiters and waitresses will dance, and so will the cook. He enjoys adding this excitement to other people's lives.

Roslyn Gellepsie

Roslyn, described as "an amazing lady" and a "force to be reckoned with," lives in downtown Concord. She says, "I am living alone by myself. I have an apartment and I like it very much." For twenty-three and a half years, she lived in the institution.

She moved about a year ago from the Lakes Region because she wanted to be near to the state legislature and to "use the Capitol." For her, testifying, writing letters to the editor, to Congress and others are all important parts of her life. She attended the People First national self advocacy conference in Nashville, Tennessee.

Betsy Bartholomew

Betsy said she's twenty-four years old and has one sister. She lives with her parents and started with self advocacy just about a year ago. She is one of the Lakes Region's co-chairpersons. In describing her personal interests, she said they included art, reading, letter writing, travel and rock and roll music.

Last year she worked with children in a college day care center which she really enjoyed. Betsy is looking forward to moving into her own place and becoming more independent. Since she's lived with her parents, she doesn't necessarily know about the problems people faced in institutions or those who are without money, but "she'll help others, (even) if she doesn't have the problems herself."

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[3]All names used in the report are pseudonymns unless otherwise noted.

T. J. Monroe[4], a leader nationally in self advocacy, was a guest speaker. He was described as "very charismatic, and certainly energized the audience." Microphone time was set up afterwards so people could talk about what their issues were too. TJ listened and gave a personal response and "so that was dynamic too." Another keynote speaker was Ruth Sinkowitz-Mercer, from Massachusetts. As another advocate described:

> She talked about being...at Belchertown in Massachusetts and being written off...People started standing up spontaneously in the audience and saying this happened to me at Laconia State School...the bureaucrats like us, were just, jaws were dropping. It was just very, very powerful listening to people share their experience and needing to be validated, to have somebody listen and say yes, I understand where you are coming from.

After the first conference, a group of 6 self advocates from 3 local groups and 3 or 4 "bureaucratic type" people met on a Saturday for a "marathon" meeting. The group decided to have another conference, get together a "help team" to assist people to put together groups, and figure out if people needed leadership skills like running meetings. Though the help team hadn't materialized yet, the second conference was in planning (and has since been held) and a newsletter was out.

The group also decided to ask about applying for a grant from the Administration on Developmental Disabilities (ADD) in Washington, DC. They made a videotape of a letter and sent it to the woman in charge "because some people don't have writing skills and they decided everybody should have a chance to be included." As one eyewitness reported:

> So they started to put their own ideas together and added them in, and they came up with a draft letter...Donna was reading sections of it, and she can read sort of well, but every once

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[4] TJ Monroe and Ruth Sinkowitz Mercer are actual names of the public speakers, not pseudonymns.

> in awhile, she would come to a word she didn't know and then there would be this kind of consultation...And people would say s, i, t, I know what that word is...It was wonderful.

The Commissioner of ADD responded and told them it was fine to go ahead. As one person described, "Wouldn't this be amazing if this group of self advocates puts a grant together and goes up against this group of Ph.D.s and comes away with it?"

Every fourth Saturday local representatives continue to come to meet in Concord, the state Capitol. The group is now officially incorporated as People First of New Hampshire with a Board of Directors, voting and non-voting members, and a part-time Executive Coordinator. She was the previous advisor in the Lakes Region and her position is funded by the arc through a grant from the Developmental Disabilities Council.

Local Self Advocacy Groups

Local self advocacy groups in New Hampshire have at least three basic functions. The first is to provide opportunities for people to talk out issues and problems, particularly in relationship to services. The second is to provide opportunities for people to connect with others socially and personally. The third is to present opportunities for people to develop leadership and organizing skills.

Both the state and local groups consist of "people with handicaps." In People First of New Hampshire, all the local groups come together and share ideas with each other. The groups are "mainly the same" in that "all of the local groups like Laconia,

Concord, Keene and all the surrounding towns...are attached to the statewide group." However, groups vary from each other and can go through different trends through the years. As one advisor explained,

> sometimes we really focus on what our goals are, and sometimes we really talk about what is on people's minds in meetings... And we've been most productive when we've listened to a person in a group meeting talk about some of the problems they might be having with staff, and the group tries to come up with resolutions for that person's problems, and the next month we ask what has transpired.

Social Activities

Social activities, such as dances, are an important part of the Laconia self advocacy group's activities. Dances seem to have several different aspects: the enjoyment of the activity, the challenge of achieving the successful outcome of the dance through group effort, and fund raising. The dances also form a part of the historical story of the group. As their treasurer described their decisionmaking about the last dances:

> We hired a group called the Boys to play for us...They're terrific...We went ahead and talked about these dances at our meetings. We talked about how we were going to do it, you know, who is going to buy what...who handles the money...who's going to help set up, who's going to decorate, that sort of thing...What we did, we all put our strength together.

People, of course, go to the dances for the same kinds of reasons that other people do, judging the dances by the same standards, such as how many people attended, if the music was good, and who was there that they met.

Activities of Local Groups

In addition to the dances, the Laconia group was also thinking about doing a booth at the Plymouth craft fair. They have a telephone tree so they can call each other. The group had the only self advocacy booth at the commemmoration of the closing of Laconia[5]. Two people also testified to the legislature about eliminating the waiting list. They prepare together for presentations, for example, at the self advocacy and case management conferences. The group puts out newsletters and meets with other groups who are starting to "sort of give out some of our information to them".

Roles Within Groups

In the Laconia group, the officers, elected by the group's members, played a central role. The group has two chairpersons, both women, a secretary, a treasurer, and a gavel keeper.

One woman described being a chairperson as "being in charge," an experience that was new to her.

> B: Well, I like being a co-chairperson. I like being in charge. I didn't think I would, but I do like it, and they do listen.
> J: What does it mean to be in charge?
> B: Oh, it means like being a boss, like in a job, someone in charge of other people, and just being in control.

She also feels that she might now be able to define herself as a

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[5]For more information on the closing of the state institution, see Racino, J. (1993). The closing of Laconia: From the inside out. Syracuse, NY: Community and Policy Studies.

leader, which was different from when she first started with the group ("I do project my voice, and that's what leaders need...to get everyone's attention.") Being a leader was equated in part with formal roles for this woman, though other characteristics were also associated with it.

> J: Do you see other people in the group as leaders?
> B: Well, only Alice. She's the other chairperson, no one else.
> J: Why do you think she is a leader?
> B: Well, she knows what she is doing. She doesn't have a high pitched voice like I do, but she knows what she is doing. And she keeps track of things. She keeps track of paperwork.

The treasurer "keeps the money and the bankbook, and keeps you up to date on how much money is taken out for food...and how much money is put in." The secretary "does the flyers" for the dances and would do "new manuals." The group also has a "gavel keeper" which "is an important role for her" and another woman who organizes the refreshments.

Roles of Advisors and Supporters

For people familiar with self advocacy, roles of advisors in these groups are often complex and challenging. Describing one of the talented advisors of the past seven years in New Hampshire, one advocate shared:

> She's thought hard and struggled with the role of the advisor, how to help people make decisions without making them yourself. I watched her in action. She'd be sitting on the edge of her chair, but waits until someone asks for help. She works at shutting up and not taking control.

This advisor, also the mother of two young children, was described

by one of the women with disabilities as "a pretty nice person to talk to." In describing her own role, the advisor referred back to the self advocacy conference she attended in 1984,

> I liked the way the advisors sat in the background and gave subtle clues whenever necessary...I always tell them (people in the self advocacy group) to shut me up when I talk too much, but whenever our local group is in a crunch, that's when I will step in and try to help guide them into a direction that seems meaningful to them, or when I am asked.

This woman described how advisors can be very directing and controlling of groups, which is not something she feels good about. For example, she has seen some advisors "take over meetings." Her own style is to lay out different options so people aren't influenced to simply do what she wants.

As a casemanager, she learned how to separate what she wants from what other people want. For example, a young father with a disability wanted custody of his child. Even though she had some personal concerns, she said "that wasn't my decision to make." She went to court with him, and decided "this is how I truly think in my heart...it should be. This is what he wants." She said "it was a great learning experience for me" and has carried over into her self advocacy advisor role.

People in the self advocacy group also have their own ideas about what advisors do, and part of their role is viewed as "overseeing" or "keeping an eye on things." Advisors will give suggestions and work with people:

> An advisor is someone who...keeps an eye on things, making sure that...we don't spend too much...I have an advisor

> working with me. He comes along with me when I go to the bank. He makes sure that we don't take out too much money.

An advisor "keeps the group together" and makes sure that people don't make mistakes or "get off track." As one young man explained: the advisors are essential, help the group to avoid major problems and keep people on important issues that can make a difference.

Future Issues in Self Advocacy

Self advocacy is in its early stages in New Hampshire, more so than in many parts of the country. While immediate issues abound, such as formation of groups, issues of control, roles of advisors and so forth, the interviews raised a number of emerging areas which are highlighted below.

Can Everyone Speak For Themselves?

One of the questions that was brought up in different forms was what self advocacy meant in the lives of people with very severe disabilities, who may not speak or move much or who may have very little ability to process information.

One advocate described how she always tried to assume that people "have opinions, ideas" explaining that she "would rather be safe than sorry." She takes the position that "they have desires and needs and wishes and preferences," though sometimes people need to develop an ability to listen with more than their ears. She sees self advocacy as approaching people in ways that support self determination for everyone.

Family Driven and Self Advocacy

People with disabilities who are involved with self advocacy are not yet an active force in New Hampshire. Yet, when the state is pushing toward a family-driven system, the question of where adults with disabilities fit in is a critically important one, but not one that is part of open discussion. As one reflective professional explained:

> This is practically heretical to say in this state at this point, but I happen to know that there are a substantial number of people who are probably living at home who don't want to live there. If you are thirty six years old, do you want to live with your mother or father?...I worry that we support families to the point that number one we are encouraging behavior that is not fostering growth and independence in people with disabilities and number two...I do not want resources to go to family support at the expense of even greater support needed for adults who are out on their own.

Parents may be reluctant for their children to move out of their home. As the independent living center staff shared: "I think sometimes parents will take a risk or a chance for themselves, but they wouldn't necessarily sort of allow, which is a terrible word, but they wouldn't maybe create a situation where that young adult would perhaps want to take the same risk for themself." The advisor in the Lakes Region is trying to find a way to reach teachers who can contact the parents to promote the involvement of their son or daughter in self advocacy. As she said: "It's not been addressed at all."

Self Advocacy and Control of Money

Financial resources continue to go into systems with only a small proportion of the money reaching the people for whom it was intended. In discussing the reasons why money is not given directly to consumers and instead goes to agencies, one administrator explained our lack of trust and need for control:

> People fear the lack of control. They'll do bad things, go buy booze, or something. The controls that we put through governmental social policies are more or less statements that we don't trust these people will make good judgments and in fact, they may not...And we'll have 45 people to manage that 5,000 dollars.

The more immediate financial issue was the one faced by People First, which had funding on a six month basis at the time of the last research visit. Describing a problem of all advocacy groups, the director said, "I want to make sure that the direction of People First isn't my direction, it is what the people want...I've got to make sure that wherever I get my money, they don't have hidden agendas for People First, too. That will be crucial."

The Disability of Mental Retardation

People with mental retardation, head injury or any type of actual or perceived "mental" or cognitive disability face stigma, including among other people with disabilities. There's a tendency for people to compare themselves to each other, and this happens even in rehabilitation hospitals where people will construct a hierarchy based on disability.

People with mental retardation or mental illness face barriers

everyday. As one woman with a physical disability discussed:

> I don't actually feel disabled until I come upon a barrier...My apartment's all accessible so I don't think about the fact that I'm in a wheelchair...until I get to a place (where)...there's stairs and I can't get in. But I would imagine that ...if it is mental retardation or mental illness, and that the barrier is that...I run into this person in the lobby of my building everyday and they're always condescending to me...That's a barrier you're faced with everyday.

On the opposite side of the coin, people with mental retardation may view people in wheelchairs as the ones who need more help. As one man explained, "We're trying to make these people in wheelchairs feel like...they've done something, making them proud of themselves. And someday, live on their own."

Self Advocacy and Power

Self advocacy as a systems change strategy concentrates on activities similar to those used in other grassroots organizing. These include: legislative testimony, letter writing to Congress, government officials, and public media such as tv stations, meetings with potential allies, and letters to the editors. Yet, strategies about what happens when someone does not respond in the way you'd like ("My responses were...you either take what we give you or take the door and leave.") do not seem to be explored. Anyone who has been involved in effective advocacy knows of the real personal risks if one's actions begin to threaten the status quo. If self advocacy becomes a force for systems change, people with disabilities may face the same types of repercussions that other advocates do.

New Hampshire's Guardianship Program

Since self advocacy is tied closely with choices and decisionmaking, the way in which guardianship operates is intimately tied with a person's freedom. This section describes some of the central features of the state's guardianship program primarily from the viewpoint of the program director who has been involved with the state program since the late 1970s and who has served as President of the National Guardianship Association.

The New Hampshire program has a number of features that make it fairly unique among the states. These include the independent versus "case management model" of guardianship, use of a functional versus a medical definition of incapacity, and heavy reliance on limited instead of full guardianship as well as other features to promote time limited use of this alternative.

Creation of the Independent Guardianship Program

The guardianship program was created by a lawsuit in which the state Supreme Court concluded that for people in an institution, specifically the state psychiatric hospital or Laconia, who were incapacitated, the state must pay for and make sure an independent guardian was provided (when no family member was willing or capable to be appointed). A separate independent corporation was established to provide both guardianship services and "less restrictive services" such as money management, representative payee, conservatorship, durable health care powers of attorney, and other surrogate functions. As one state administrator shared, this

independence from the state system means that "decisions as much as humanly possible are (based) on information and the needs of individuals (rather) than the needs of the system."

Functional Definition of Incapacity

The law in New Hampshire specifically disregards medical definitions and is interested solely in what a person can or cannot do. This means instead of a finding of incapacity based on I.Q. or a certain disease or condition, the law is built around functional assessment. In combination with that, the law requires that a guardian just be given authority over the areas in which the person is actually incapacitated.

Limited versus Full Guardianships

The director reported that in New Hampshire about 90% of the guardianships are limited in some way, whereas his experience in other states is that 0-10% are limited. In New Hampshire, for people with developmental disabilities, whomever has the prime responsibility for providing services to the person (e.g., area agencies) also has the responsibility to determine whether a guardianship petition should be filed. The two key factors for filing for guardianship are that there must be a severe incapacity and that incapacity has to lead to the likelihood of harm.

Independent versus Casemanagement Model of Guardianship

In New Hampshire, according to the state law, no one who works

with a person on an individual professional level can be a guardian. When public guardians are used, for example when family members are not available or appropriate because of abuse, guardians are prevented by law from providing services. The guardian is considered free to be a decisionmaker instead of a casemanager, and to the extent feasible, conflicts of interest are minimized. For example, the model helps to stay away from situations where the person is told "you do what I want and you'll get your money this week."

The other side of this story is that a person with a disability might end up needing to be responsive to one set of rules where they live, such as in foster care, and also to another set of rules established by a guardian who may be miles away and reachable only be telephone. Guardians, too, can treat people like children and continually ask people to prove themselves and act according to the guardian's standards. As one woman with a disability described:

> Sometimes we expect people with disabilities to be able to fit this pattern exactly perfectly before they're allowed to get this golden apartment or whatever it is.

The person herself may be faced with the decision of whether to do what she feels is right or to say what the guardian wants to hear because then she will be given more freedom.

Guardianship Review and Code of Ethics

There is also a requirement in the law that guardianships be

reviewed every year (although reportedly this does not always occur). This review is to take place in front of a judge, pursuant to a report filed by the guardian. The guardian must state why the guardianship is still necessary and why it should not be limited. This is a very important provision especially for "developmentally impaired folks who...with good services, and I think they're real good in New Hampshire, are constantly gaining more ability to make decisions about their own needs and their own lives."

This guardianship office has also developed a code of ethics on how one makes decisions for people. Some of the principles are:

> (to) know what the client wants and (to)...do whatever the client wants whenever that is possible...unless there is some substantial and immediate kind of harm...And even in those cases, in individualized situations, we still might be able to build a good case for doing what the client wants. It's really a matter of how informed they are about the results of doing what they want and whether they...can deal with the result of doing what they want.

Changes in "Guardianship World"

At the time of the 1970s Garrity versus Gallen legal actions[6] a large number of guardianship petitions were filed, partially because some people were subjected to a lot of abuse and may have been abandoned in the institution by their families, who relinquished all responsibility for their son or daughter. Compared to other groups, people with developmental disabilities are now a smaller proportion of the caseload of the Office of the Public Guardian and this keeps decreasing as years go by.

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[6]For more information, see Racino, J. (1993). Garrity v. Gallen: The role of the court in institutional closure. Syracuse, NY: Community and Policy Studies.

Most of the changes in the "guardianship world" are coming from the population of vocal elders who used "grassroots legislative advocacy" to force legislators to look at these issues. Especially as people are living longer and tend to be dying of chronic as opposed to acute illnesses, guardinaship issues potentially can affect everyone. Recent changes that are occurring, such as in money management programs, though targeted at elders, can also positively affect people with developmental disabilities or mental health labels.

Conclusion

Whether viewed through the lens of self advocacy, of the decisions and concerns of people with disabilities, or through the efforts to limit guardianship intrusion in people's lives, this case study suggests that the future roles of people with disabilities in their own lives in New Hampshire are still largley unknown. Probably more so than in any other area, the following describes the course that is being traveled with the bend still not turned in the road:

> The change occurs because you are traveling along a road, as a metaphor, and every step you take changes the horizon because you are looking at it from a different place. That's how it occurs. You cover a stretch of road, you look up and say I didn't know the river was down there...Maybe I better get ready to fiord it. And then you travel a little further and maybe you cross the river and say, oh my gosh, there are mountains up there. It's going to be cold up there and I'll need to find a way through the mountains. That's how it happens.

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